



# Living One's Dying:

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Letting Go is Not Giving Up.

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# Phenomenology

Attempts to explore and understand the essence of an experience

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- Origins in philosophy
- Looks for universal truths within the individual experience
- Embraces complexity
- Searches for patterns
- Supports pluralism
- Explores meaning
- Begins with a question

“What is the experience of surrendering to one’s dying?”



# Definitions:

Establishes the boundary of experience being investigated...

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|----------------|---|
| "What is"      | An open searching into the complexity, depth, or character of something."                         |
| "Experience"   | A passing through or adjusting to a particular set of circumstances.                              |
| "Surrendering" | Allowing one's self to rest in the act of being.  |
| "One's"        | An entire being; biological, psychological/emotional, cognitive, social, cultural, and spiritual. |
| "Dying"        | The process of moving into the state of death.  |



# Criteria for Selection of Co-Researchers \* (12)

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- Physically able to tolerate a 1-2 hour open-ended, unstructured interview.
- Emotionally willing to reflect on and explore the question.
- Alert & Verbal.
- Willing to be tape recorded.
- Willing to sign a release to use their responses in the research study and perhaps later for publication.


\* Humanistic Research Models refer to “research subjects” as...



# Textural Themes: (The What?)

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1. Remembering a Significant Personal and/or Family Loss During the Process of Dying. (9)



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"My Dad was about 5 or 6 when his Mom died...he can help him (Adam, her three year old son) through it too."

"They gave her (Sandy's Mother) aggressive chemo, she be talkin and laughin and when she came back... she didn't know nobody."


(Raped at age 6) "I didn't tell...I dealt with it myself."



# Textural Theme

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2. Experienced the Diminished  
Quality of Life of Family/  
Friends Treated for Cancer (8)



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"...my husband's quality of life was over...  
there was no time that anything was any joy...my husband  
was either going in and out of the hospital or he was  
very very sick...there was nothing."

"...they (other cancer patients) look like zombies...  
aliens from another planet."


"You know when he (her Father) was sick his world just...  
it fell apart...he was very very sick...very sick...but he didn't talk to me.  
He did not look at television. He didn't read the paper...he had no  
contact with anything going on..."



# Textural Theme

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3. Experiencing the Deterioration of the Physical “Self”...the Threat of the Loss of the Psychological/Emotional “Self”. (9)




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"I laid awake one night crying...I thought everything over...this is only the beginning...this isn't something you're locked into...you have a choice...I'd rather have less time but good time."

"Three years ago...I was not the person you see here...I'm a totally different person...it's a lot to lose in 3 years."

"You be sayin, it (cancer) make me somethin I ain't."



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"The doctor told me he would give me chemo that would really make me sick, you know real real sick...I was thinkin, I was already sick...I told him no."

"Am I gonna lay in bed as a vegetable because of it (chemotherapy)? I don't want that...I'm gonna live while I'm here."




# Textural Theme

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## 4. Acknowledging a “faith-based” Surrender.

- Intensification of living. (6)
- Living in anticipation of transcendence and/or transformation. (6)




"I'm gonna do what I can while I can...I wanna take part in everything that I can while I'm here."

"My kind of religion is whatever I was doing."

"I've always felt I didn't have to be in church...  
wherever you are...you're with God."

"I don't feel that I'm going to nothing, I just don't know what I'm going to...I couldn't possibly know that."



"The Lord has the last word." "I'm ready to go...if he ready for me, I'm here, I'm willing to go. I head home and have peace."

"I've learned not to worry cause He'll take care of me."

"I've prepared myself...to leave you know....it's just like taking a plane ride, you can't wait to get to... your destination."

"...if the time comes and it's time for my transition, then we'll bless the moment and go rest on the other side..."

# Seven Universal Structures (The How?)

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## **Causality/Fate**

"I feel when I was born, my time was written down someplace."

## **Relationship to Self**

"They (doctors) wanna prolong life, but if you gotta break yourself down to prolong life..."

## **\*Relationship to Others (11)**

"When someone dies...it's hardest on the people left behind. I'm hoping that the way I'm doing this is...gonna make it easier on them (her children)."

## **\*Bodyhood (12)**

"You can prolong my life, but I'll be sick for my prolonged life."

## **\*Temporality (12)**

"I'll come into the doctor and you got a three hour wait for an appointment. People are borrowing **MY TIME**, they are using **MY TIME**, taking it away from me."

## **Spatiality**

"I think you surrender to things all your life."

## **Materiality**

"Once you there (heaven), you know it's just...just free air."



## Criteria/Questions that Insure Validity:

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- Did the interviewer influence the contents?
- Is the transcription accurate?
- Were there conclusions other than those offered by researcher that could have been derived?
- Is it possible to go from the general structural description to account for the specific contents and connections?
- Is the structural description situation-specific?



# Implications for Care:

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## **Textural Theme #1: Remembering a significant personal and/or family loss.**

- Complicated intergenerational grief shapes the family narrative.
- The identification with the evolution of loss & grief within the context of the family narrative.
- Revisiting historical loss & grief issues.
- Attempts to validate & reconcile historical loss & grief issues.
- Lineage as strength: “reaching back” to ancestors for guidance, comfort, support, & courage.
- The heart is broken “open”: secrets, regrets, love, & unfinished grief work seeps out.



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## **Textural Theme #2: Recalling diminished quality of life for family & friends.**

- Painful memories of loss & grief shape treatment decisions.
- Healing 'into' death shifts the family narrative and gives meaning to one's dying.
- The family narrative is transformed when the story of "dying" ends well.
- Want to pass onto children & grandchildren "how to die" as one of the lessons learned in life (legacy).



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### Textural Theme #3: The threat of the loss of the psychological/emotional self.

- Shifting the family narrative from one of subtraction to one of addition & multiplication.
- Want to shift the family conversation away from bodily cure to dying healed/whole.
- A time of crisis creates a permeable membrane for the passing on of “life” values.
- Discovering the “I or me” in the family narrative.
- Awareness of time; “borrowing **my** time’, “using up **my** time”, stealing **my** time”.



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## Textural Theme #4: Faith-based Surrender

- Culturally sensitive care related to placement of hope in the present or future.
- Life can have multiple hopes which can co-exist.

### **4A:**

- Hope focused on the present moment: immortality created through living the moments & creating memories.

### **4B:**

- Hope focused on the future; immortality, justice, freedom, & reunion with family & friends.
- Transcendence & Transformation, the promise foretold in the reading of the Scriptures.



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## References

Provided upon request